

Senate Bill 360 An Act Concerning P.A.N.D.A.S.

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Thank you for hearing the PANDAS stories today. I look forward to the Informational Forum on March 1, 2013.

Since you've already heard testimony from others telling their stories of how their children and families have been affected by PANDAS, I'm going to just share with you some statistics:

My daughter is 15 ½ years old, a Sophomore in high school.

Her onset of PANDAS/PANS seems to have been 5 years ago, in the autumn of 5th grade. However, we believe it started much earlier, probably with less symptomatic manifestations, and it was missed then, as well.

Prior to her 5th grade year, my daughter was a normal, highly functioning child being considered for Gifted and Talented programs, attending scholarly programs at Manchester Community College, enjoying her school orchestra, playing viola and piano, loving her school and her friends, going to birthday parties, eating normally, participating in Yearbook Club, and going to art school and summer camps.

That all stopped in November of her 5th grade year. Her life (our lives) have never been the same; what you'll hear from ALL of the PANDAS parents and children's testimony is one common theme: suddenly their child was not the same, the family was held hostage by an invisible demon, and no one could help them.

Now for the statistics:

Physical Symptoms:

- 34 Upper Respiratory Infections
- 5 urinary tract infections
- 8 diagnosed strep infections
- 10+ bothersome mystery rashes
- 12 Incidents of joint pain, back pain, stiffness
- 20 "virus" diagnosis with no other explanation
- Numerous diagnosis of pharyngitis
- Numerous "croup" visits to the doctor and ER
- Reflux requiring medications 5 times per day
- Bedwetting/enuresis
- Chronic fatigue, exhaustion
- Trouble hearing, with no reason
- Dilated, fixated pupils
- Weight loss

Total: over 100 incidents of physical symptoms

- 1 ENT
- 1 GYN
- 2 eye doctors
- 1 audiologist
- 1 rheumatologist
- 1 urologist
- 1 trichotillomania specialist
- 1 support group led by a psychologist
- 3 hospitals
- 2 mental health clinics
- 3 school psychologists
- 3 school social workers
- 3 school nurses

Total: 33 professionals and organizations, not including walk in clinics and urgent care facilities had seen my daughter and MISSED the diagnosis, misdiagnosing her wrongly and wasting time and money.

Psychotropic Drugs

- Prozac
- Celexa
- Abilify
- Ativan
- Clonopin
- Visteral

Total: 6 psychotropic drugs used in various dosages, protocols, and at various times of day. NOTHING helped. NOTHING worked. SHE WAS WORSE (common for PANDAS children due to receptors in the brain not responding well to these drugs, making them even more dangerous for pediatric use)

My daughter was finally diagnosed with PANS/PANDAS in November, 2012.

We were told about PANDAS at a mental health clinic in Philadelphia in February, 2012. It was missed by every other professional!

But that wasn't the end of the story.

What has happened since we heard about PANDAS?

- 8 months of finding the right doctors who knew what to look for and run tests
- 6 more months wait to get into one of only THREE immunologists in the USA that know how to diagnose and treat PANDAS/PANS
- 32 very telling blood tests revealed many answers to my daughter's illnesses, and many mysteries finally have been solved.

Where is she now?

- 1 pediatrician
- 1 therapist
- 1 pediatric neurologist
- 1 immunologist (April 2013 – made the appointment in Oct 2012 – long wait)